



Services for Children with Autism

Alliance supports expanding services for children with Autism Spectrum Disorder (ASD). ASD and autism are general terms for a group of complex disorders of brain development characterized by difficulties in social interaction, verbal and nonverbal communication, and repetitive behaviors. One out of every 101 children in Colorado is affected by ASD.

HB 15-1186: Expanding Services for Children with Autism

Colorado's Children with Autism waiver provides intensive behavioral therapies for children with ASD who require long-term services and supports in order to remain in their family homes or community. Community-Centered Boards provide case management services for these children. Because of the current enrollment cap, this waiver has been a very small part of services offered by CCBs and Program Approved Service Agencies. The waiver should be expanded because:

- Research shows intensive behavioral intervention is most effective when started early at younger ages.
- The waiver is currently capped at 75 children, with 320 children on the waiting list.
- On average, children wait 2.5 years before being enrolled into services. As a result, they receive an average of less than 1 year of services before aging out.
- Some children wait so long that they never receive services before they age out.
- The bill will eliminate the waitlist, allowing children to receive services as soon as they are diagnosed and most receptive to treatment.
- The bill will ensure that all children who enroll by their 8th birthdays can receive three years of services.

SB 15-015: Mental Health Parity for Autism Spectrum Disorders

This bill aims to correct an existing conflict between state and federal laws with respect to mental health parity and coverage for ASD in commercial health plans. The bill would:

- Clarify that ASD is a mental disorder for purposes of mental health parity laws, and, thus, coverage for ASD must be no less extensive than that provided for a physical illness.
- Require coverage of ASD services in health benefit plans without limits on the number of medically necessary services or visits.
- Bring ASD benefits in line with the essential health benefits described for a physical illness under the Affordable Care Act.



Testimony for HB-15-1186

Submitted by: Sharon S. Jacksi, CEO

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STRIVE supports the proposed legislation that will enhance the Children with Autism (CWA) program by 1) expanding eligibility from ages six to eight, 2) allowing children a full three years of service, and 3) eliminating the enrollment cap. These legislative changes will greatly enhance families' ability to secure treatment in a timely and cost effective manner. With the current limit of 75 available enrollments and 300+ on the wait list, the majority of children are not able to receive the benefits of early behavioral interventions due to "aging out" before the program is available to them. Because so few enrollments are available, many families are not even applying for the program and, instead, are relying on a patchwork of services that do not adequately address their children's needs.

While the Family Services and Supports Program (FSSP) can provide limited funds for assessment and initial consultation, on-going annual costs of \$25,000+ for treatment are not available in this program, where STRIVE's annual funding for families is \$1,000 or less. The Children's Extensive Support Medicaid waiver (CES) has provided some options for families, but only for those children profoundly impacted by autism. In 2012, STRIVE began an evaluation and Applied Behavior Analysis (ABA) treatment program (Audyssey) for children with potential Autism Spectrum Disorder (ASD), but funding has primarily relied on donations and special events, an unstable funding source at best. While families receive an evaluation, diagnosis, and initial consultation, funds are not available for ABA treatment. Our Audyssey program assesses 60+ children per year and identifies 5-7% with autism. STRIVE currently has 13 children requiring intensive autism treatment, none of whom are able to access the CWA waiver. Less than 10 per cent of these families have insurance or other means of payment, so they are receiving less than medically necessary services. It is critical that state and federal support be added for all these families so that they are not on a wait list for years.

The numbers indicated above, however, are not necessarily reflective of the need for service. An issue in Mesa County is the low early identification rate for ASD based on population projections. Only a small percentage of children are identified in preschool years, while most wait until the school years for an educational qualification for autism. These families are concerned about their children's behavioral, social and communicative challenges but do not have financial resources to secure services. The proposed legislation, which allows for earlier access and funding, should result in earlier identification when treatment is most effective. Early access and identification is critical for implementing behavioral intervention treatment that is extensive and intensive in

nature (Matson and Smith, 2008). Evidenced-based behavioral interventions of 30+ hours per week for two-three years are recommended (Peters-Scheffer et al., 2011).

Since many children are not diagnosed until school-age due to lack of evaluation and treatment options, extending the age limit to 8 is equally critical to offering adequate treatment. That, in combination with the three-year treatment option included in the proposed legislation, is consistent with research results regarding the timing and intensity of behavioral treatment (Matson and Smith, 2008).

On behalf of STRiVE and Mesa County children with autism and their families, I strongly urge your support for the proposed legislation.

References

Matson, J.L. and Smith, K. M., (2008). Current status of intensive interventions for young children with autism and PDD-NOS. *Research in Autism Spectrum Disorders*, 2, 60-74.

Peters-Scheffer, et al., (Jan-Mar 2011). Meta-analytic study on effectiveness of comprehensive ABA based EI programs for children with ASD, *Research in Autism Spectrum Disorder*, Vol 5 (1) 60-69.